

**Special Medical Services
INFORMATION AND REFERRAL
SFY 2006**

New Hampshire Department of Health and Human Services
Division of Community Based Care Services
Bureau of Medical Services
Special Medical Services Section

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About Information and Referral

The New Hampshire Title V Program for Children with Special Health Care Needs, Special Medical Services (SMS), provides information and referral regarding children with special health care needs as a public service. Children with special health care needs (CSHCN) are defined as those who have or are at increased risk for a chronic physical, developmental, behavioral or emotional condition, and who also require health and related services of a type or amount beyond that required by children generally¹.

The SMS information and referral (I&R) service is available through telephone access, the SMS website, e-mail, and paper correspondence. The service is provided directly by SMS staff and via state-funded contracts with other providers. This report does not include data from the contracted organizations (NH Family Voices, Parent-To-Parent of NH), which submit their own separate annual reports.

The Information and Referral Report has previously been prepared on a calendar-year basis. Beginning with State fiscal year (SFY) 2004-2005, Special Medical Services converted to state fiscal year reporting. The I&R database now includes web-based inquiries reported from the State website in addition to the telephone inquiries.

The data, combined with reports from the contracted services, are being used to improve the overall public information and referral system for CSHCN in New Hampshire by providing accurate information for SMS policy discussions, program planning and budget allocations.

The Special Medical Services information and referral number is 1-800-852-3345, Ext. 4488. E-mail inquiries can be directed through the NH Department of Health and Human Services website at www.dhhs.state.nh.us.

¹ McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics*. 1998;102:137-140.

Information and Referral FY'06 Report

The Special Medical Services (SMS) public help-line received 220 telephone inquiries about health-related subjects and concerns from July 1, 2005 through June 30, 2006 (Figure 1). The number of direct calls to SMS for information and referral (I&R) continues a steady downward trend, from 1,069 in 1995. This trend is partially the result of transitioning direct care services and specialty clinics to the private sector. More specifically, it is due to the SMS decision to contract with community-based organizations to provide information and referral to the public via their own telephone and web sites.

This SMS I&R Report does not include the calls to these contracted providers (i.e., New Hampshire Family Voices and Parent-to-Parent of New Hampshire). That data is reported separately by these organizations and averages 1,200 calls yearly. Combined with the direct SMS calls, this indicates over a 24% increase in volume over the past ten years. The external I&R services that SMS funds through these contracts makes a major contribution to the enhancement of public access to specialized information and referral and supports families and others concerned about children with special health care needs.

Of the 220 calls received directly by SMS, 75% were in reference to children (Figure 2) and 51% (n = 112) were from a parent, family member or friend (Figure 3). Hillsborough, Rockingham and Merrimack counties contributed over 59% of the calls where the county was known (Figure 4a). Merrimack County, however, contributed the highest call rate based on the county population (Figure 4b).

The conditions that callers have commonly referenced over the past several years have been assigned to broad categories for reporting purposes. Over 200 specific medical and psychiatric diagnoses were reviewed prior to database programming by a team of pediatric physicians and the Section Administrator for Special Medical Services. Diagnoses were assigned to 19 categories or Condition Groups (Table 1). In FY 06 there were 172 condition-specific calls. The top five health categories referenced were:

- Nervous System/Brain (20%)
- Autism (10%)
- Developmental Issues (8%)
- Genetic/Birth Defects (4%)
- Mental Health (8%)

Table 2 lists the broad Condition Groups and the number of calls referencing each group.

Caller concerns are grouped into broad themes: Health, Support, School, Literature, Respite, Basic Needs and Other/Information. Approximately 30 sub-topics are included within the groups (Table 3). Approximately 33% of the calls reference multiple concerns; therefore, the number of concerns at 100% (n=292) exceeds the number of single calls at 100% (n=220). Health issues constituted 71% of the concerns referenced (Figure 5).

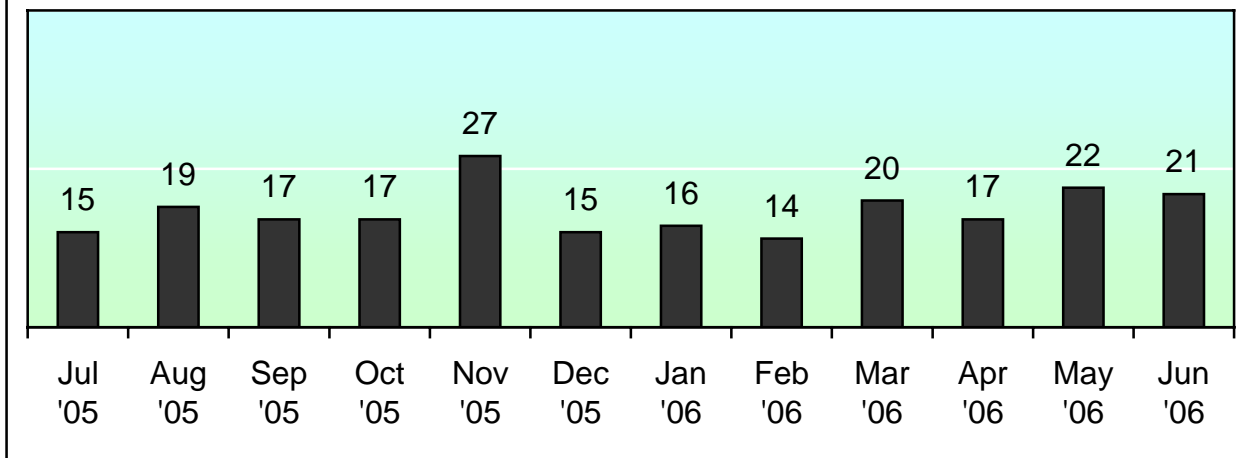
Where age was referenced, approximately 8% of the calls were in regard to adults over age 20. Children between the ages of birth and 4 were referenced in 31% of the calls where age was identified (Figure 6). Forty-seven percent of the calls were in regard to children between 5-14 years of age.

The services rendered by SMS staff responding to calls for information and referral are grouped into 6 broad categories: Emotional Support, Verbal Information, Parent Match, SMS Application, Written Materials Sent, Technical Assistance and Other (Table 4). The primary service was the provision of verbal information (61%), followed by mailed materials and emotional support (9%) (Figure 7). Multiple services were provided for 69% of the callers. Applications for SMS services were sent to 17% of the callers.

Those responding to information and referral calls made 292 referrals to a wide variety of agencies, services and organizations (Figure 8). Over 33% of callers received more than one referral. Referrals to statewide and community organizations constituted 51% of referrals. These organizations are comprised of parent groups, health care providers, specialty providers, local town services, Area Agencies and other local resources. New Hampshire State agencies constituted 48% of referrals. State offices include welfare district offices, the Social Security Administration, the Department of Education, Maternal and Child Health/WIC, Medicaid/Medicare, the Division of Children, Youth and Families, Special Medical Services, and other State agencies. Special Medical Services was a referral for 27% of callers or about half of the State referrals. Table 5 provides a detailed enumeration of the referrals made.

SMS coordinators responded to 86% of the calls, with 14% of the calls being handled by other staff (Figure 9). Approximately 61% of the calls were resolved within 15 minutes; 27% involved up to a half-hour and 2% exceeded one hour in duration (Figure 10).

Figure 1: Calls per Month



Total number of calls for FY 2005-2006 = 220

Figure 2: Call is About

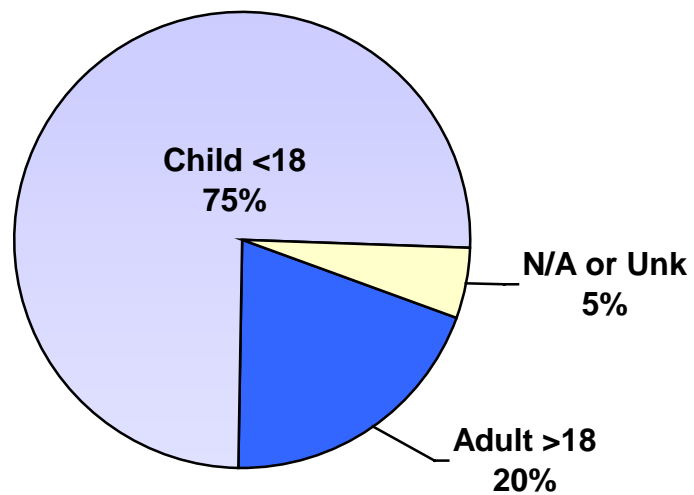
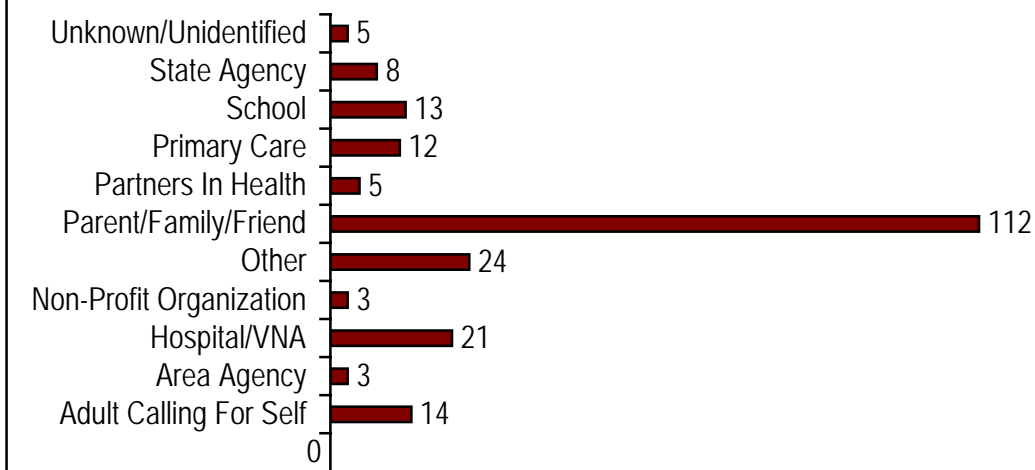
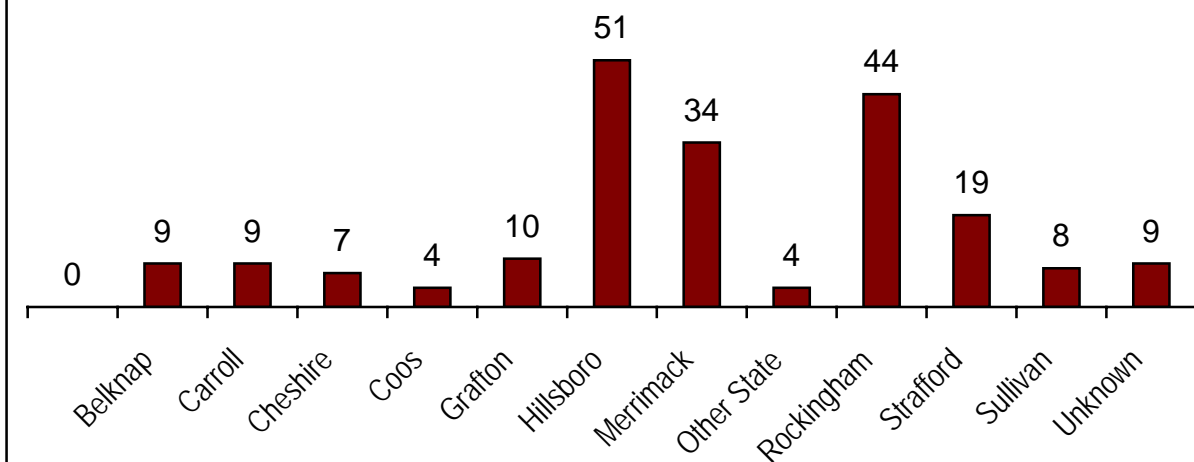


Figure 3: Source of Call



N = 220

Figure 4a: Distribution of Calls by County*



*Not all calls coded by county

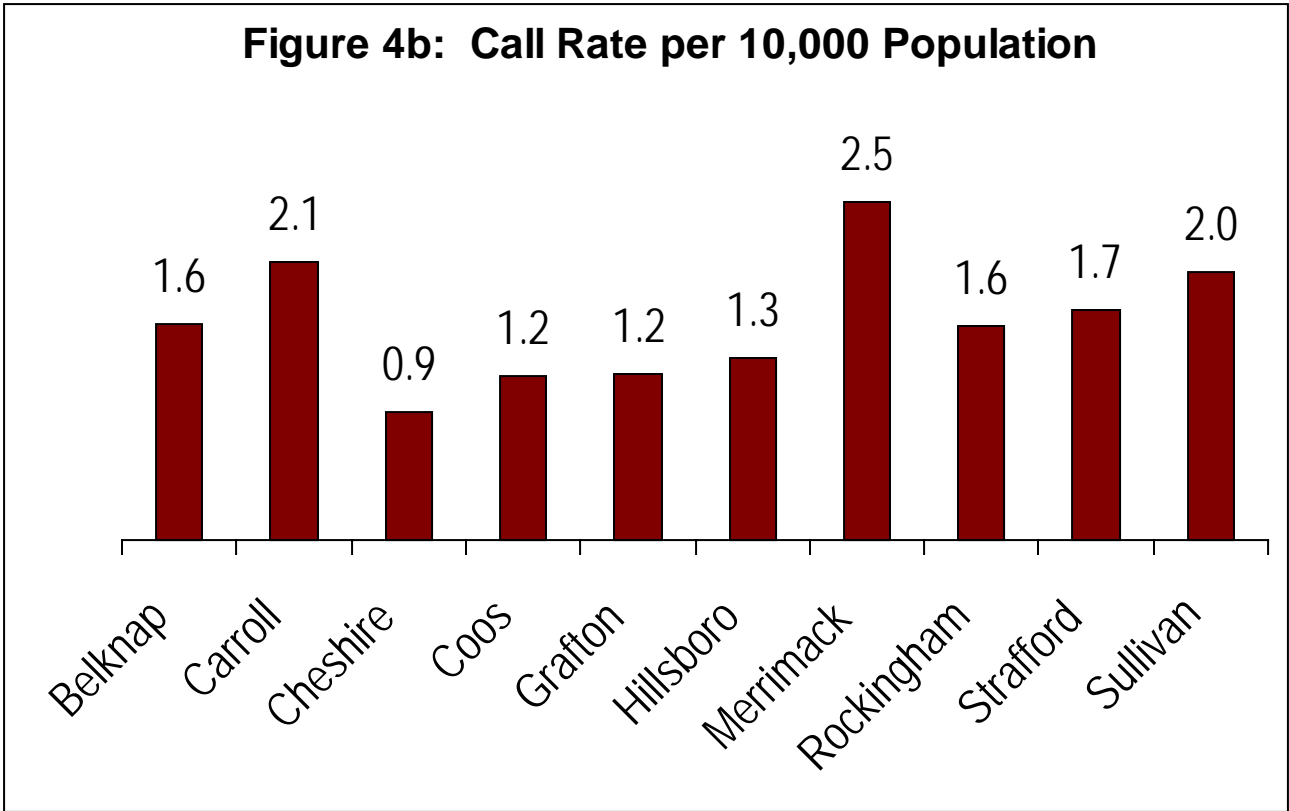


Table 1: Master List for I&R Calls: Health Conditions Commonly Referenced

Reporting Groups	Examples
Allergies	Adverse drug reaction, environmental, food allergies
Autism	Asperger's Syndrome, autism, autism spectrum disorders (ASD), pervasive developmental delay (PDD)
Cardiac	Cardiac anomalies, cardiac transplant, congenital heart, heart problems, heart surgery, hypoplastic left heart Syndrome (HLHS), patent ductus arteriosus (PDA), tetralogy of fallot, ventricular septal defect (VSD)
Development	Delayed speech, developmental delay (DD), failure to thrive, mental retardation (MR), prematurity,
Endocrine/Metabolic	Diabetes, hyperglycemia, phenylketonuria (PKU)
Gastro-intestinal/Genito-urinary	Bed wetting, Chron's Disease, chronic constipation, colitis, digestive disorders, dysphagia, G-tube, gastric bleed, gastroenteritis, Hirschprung's Disease, hypospadias, illiostomy, J-tube, open bladder, Prune Belly Syndrome (PBS), reflux disease (GERD), renal disease, ulcerative colitis, ulcers, vomiting, weight gain
Genetic/Birth defects	Adrenal leukodystrophy (ALD), chromosomal abnormalities, chromosomal deletion, cleft lip, cleft palate, congenital diaphragmatic hernia, Down Syndrome, Dubowitz Syndrome, femoral hyperplasia facies syndrome, fetal alcohol or drug syndrome or effects (FAS/FDS, FDS/FDE), Fragile X Syndrome, Marfans Syndrome, Martin-Bell Syndrome, multiple congenital anomalies (ECC Syndrome), neurofibromatosis, Noonan Syndrome, osteogenesis imperfecta, Pfeiffer Syndrome, Prader-Willi Syndrome (PWS), Proteus Syndrome, Rubenstein-Taybi, soft palate insufficiency, trisomy 9, trisomy 21, tuberous sclerosis
Other health condition	Abuse, assault, burns, chronic health conditions/unspecified, complicated pregnancy, dental, lead poisoning, medication issues, orthodontia concerns, sudden infant death syndrome (SIDS), unnamed health condition, unable to categorize within available selections
Hearing/Vision	Blind, deaf, glaucoma, hearing impaired, Moebius Syndrome, Stargardt's Disease, vision impaired
Hematological	Hemophilia, leukemia, sickle cell disease, X-linked hypogammaglobulin anemia
Infectious disease	Cytomegalovirus, hepatitis, HIV/AIDS, meningitis, tuberculosis (TB)
Mental health	Anxiety disorder, attachment disorder, attention deficit disorder (ADD), attention deficit hyperactivity disorder (ADHD), bi-polar disorder, depression, oppositional defiant disorder (ODD), reactive attachment disorder, schizophrenia, serious emotional disturbance (SED), substance abuse
Musculoskeletal system	Amputation prothesis, arthrogryposis (no biceps), chronic fatigue, fibromyalgia, juvenile rheumatoid arthritis (JRA), low tone, Lupus, muscular dystrophy, orthopedic, torticollis
Neoplasms	Cancer, Hodgkins Disease, leukemia, myosarcoma, osteosarcoma, retinoblastoma

I&R Health Conditions Referenced by Callers (cont'd)

Reporting Groups	Examples
Nervous system/brain	Agenesis of the corpus callosum, anacephaly, apraxia, ataxia, Canavan's Disease, cerebral palsy (CP), cerebrovascular accident (CVA), dyslexia, dyspraxia, dystonia, encephalitis, epilepsy, familial spastic diplegia, Huntington's Chorea, Hurler Syndrome, hydrocephalus, hypotonia, Landau Kleffner Syndrome (LDS), learning disorders (LD), Lennox Gastaut Syndrome, medium chain acylCoAdehydrogenase (MCAD), microcephalus, mitochondrial disorder, mitochondrial myopathy, neurodevelopmental delay (NDD), neuromotor issue, non-verbal learning disability (NLD), Opsoc/Onus-myoclonus Syndrome, paraplegia, quadriplegia, Rett Syndrome, schizencephaly, seizure disorder, septo optic pituitary dysplasia (SOPD), spina bifida, spinocerebellar, stroke, Sydenham's Chorea, Tourett's Syndrome, traumatic brain injury (TBI)
Not a health issue	Issues such as insurance questions, needing help with social or community services, seeking help with medical bills
Respiratory: Asthma	Asthma
Respiratory: Cystic Fibrosis	Cystic Fibrosis (CF)
Respiratory/Circulatory: all other	Churg Strauss Syndrome, intubated, pneumonia, pulmonary condition, pulmonic valvular stenosis, reactive airway disease, subglottal stenosis, trach dependent
Dental	Orthodontia, oral health
Not listed	Not listed

Table 2: Number of calls per condition

Code	Condition Group*	FY 06 Calls
A	Allergies	3
B	Autism	22
C	Cardiac	15
D	Development	18
E	Endocrine/metabolic	6
F	Gastro-intestinal/genito-urinary	11
G	Genetic/birth defects	20
H	Health conditions and issues not categorized elsewhere	9
I	Hearing/vision	17
J	Hematological	1
K	Infectious disease	2
L	Mental health	17
M	Musculoskeletal system	9
N	Neoplasms	11
O	Nervous system/brain	43
P	Not a health issue	3
Q	Respiratory: Asthma	2
R	Respiratory: Cystic Fibrosis	4
S	Respiratory/circulatory: all other	1

- Condition not reported for all calls
N = 214

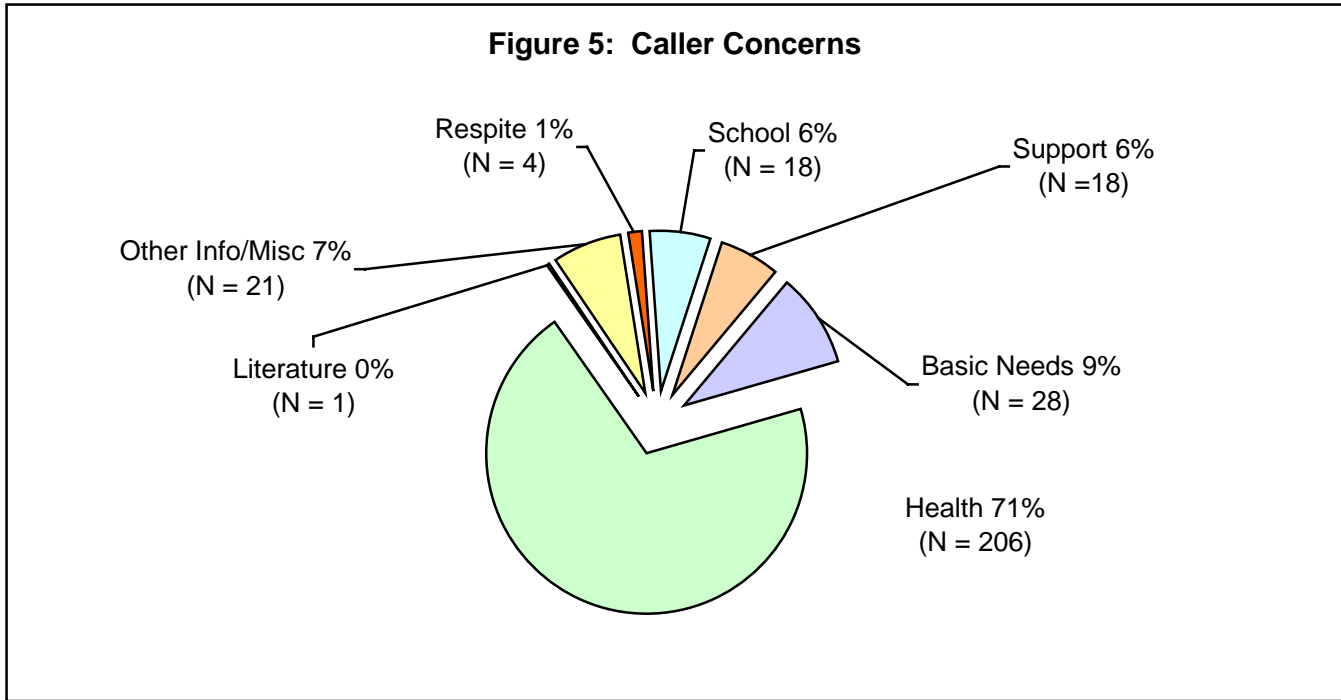


Table 3

Information and Referral Caller Concern Groups

Health generally relates to finding and accessing primary and specialty services, or technical assistance, for a wide variety of conditions, as well as health-related financial concerns such as Medicaid, insurance, SSI and help with medical bills. -

Support generally includes listening to parents, finding self-help groups, sibling support, or supports related to parenting, child custody and so on. Parent matches are requests to link one family with another family for the purposes of support. Agency connections include linking consumers and/or professionals with local, state or national resources.

School requests generally relate to help with advocacy for specific school programs or services, transition to school, transition to post-school, special education issues or job training opportunities.

Literature generally includes requests for specific publications, lending library books, condition-specific information for parents, professionals or students in secondary and post-secondary schools. It also includes requests for agency informational brochures and Internet resources.

Respite generally relates to concerns about daycare, recreation issues or home health care to provide the primary caregivers with temporary relief from responsibilities.

Basic Needs generally relates to inquiries regarding food, shelter, clothing and transportation.

Other information generally includes requests for information not classified elsewhere, or concerns about issues not otherwise categorized such as adoption, disability-related advocacy, training needs or legal assistance.

Figure 6: Age Referenced

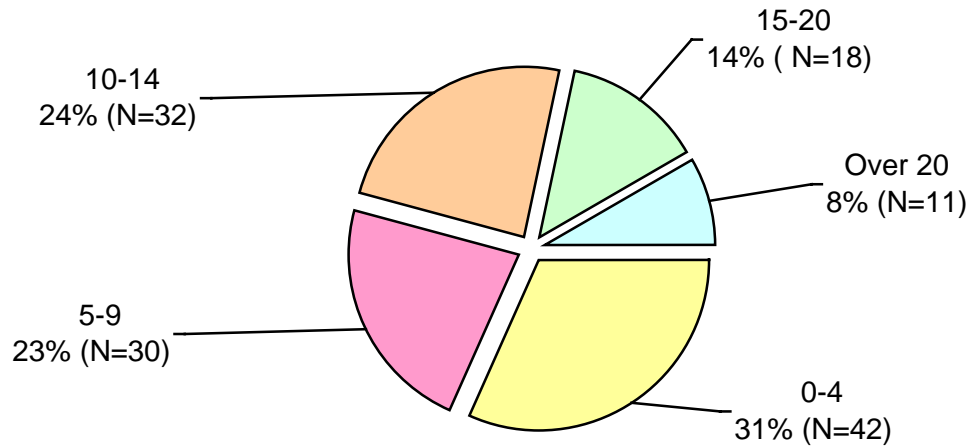


Figure 7: Services Provided

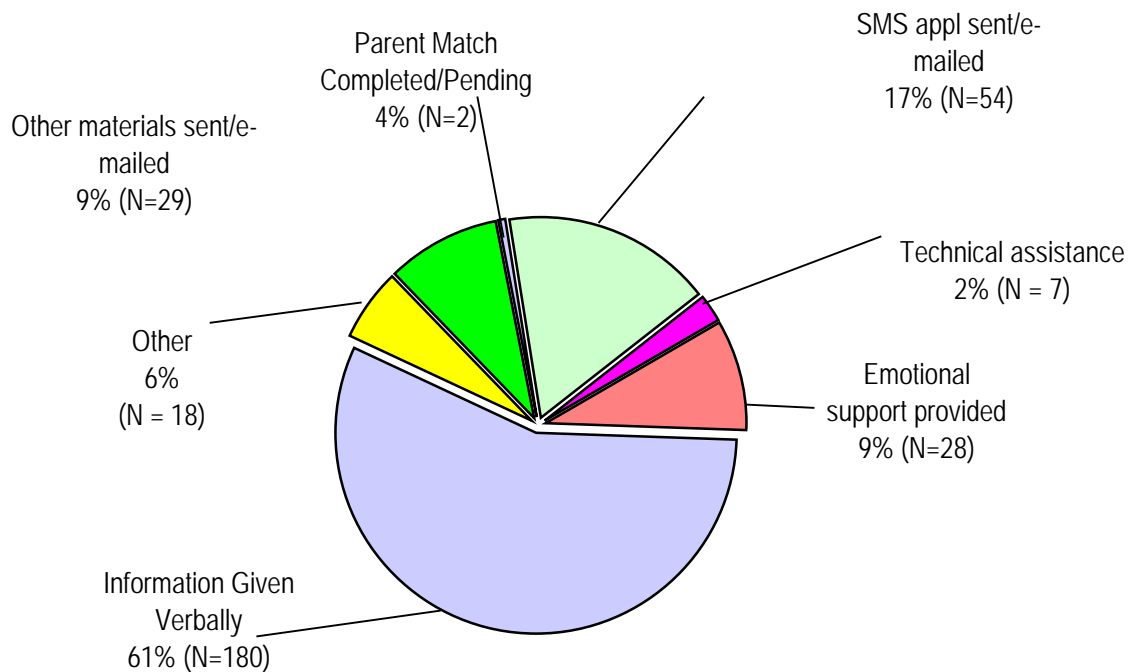


Table 4

Information and Referral Services Provided	
Materials Sent	generally refers to the provision of literature, written correspondence (including e-mail) and the mailing of applications.
Verbal Information	generally refers to telephone communications about any topics, conditions or services.
Emotional Support	generally refers to empathic listening and problem solving.
Parent Matching	refers to linking a parent with another parent for ongoing support and information. The Parent-to-Parent Upper Valley Support Group provides this service under contract with SMS, and reports that data in their annual report.
Technical Assistance	generally refers to the provision of consultation, or assistance in the area of advocacy, or with coordinating meetings or groups.
Other/Unknown	refers to services not captured by the other categories or not reported.

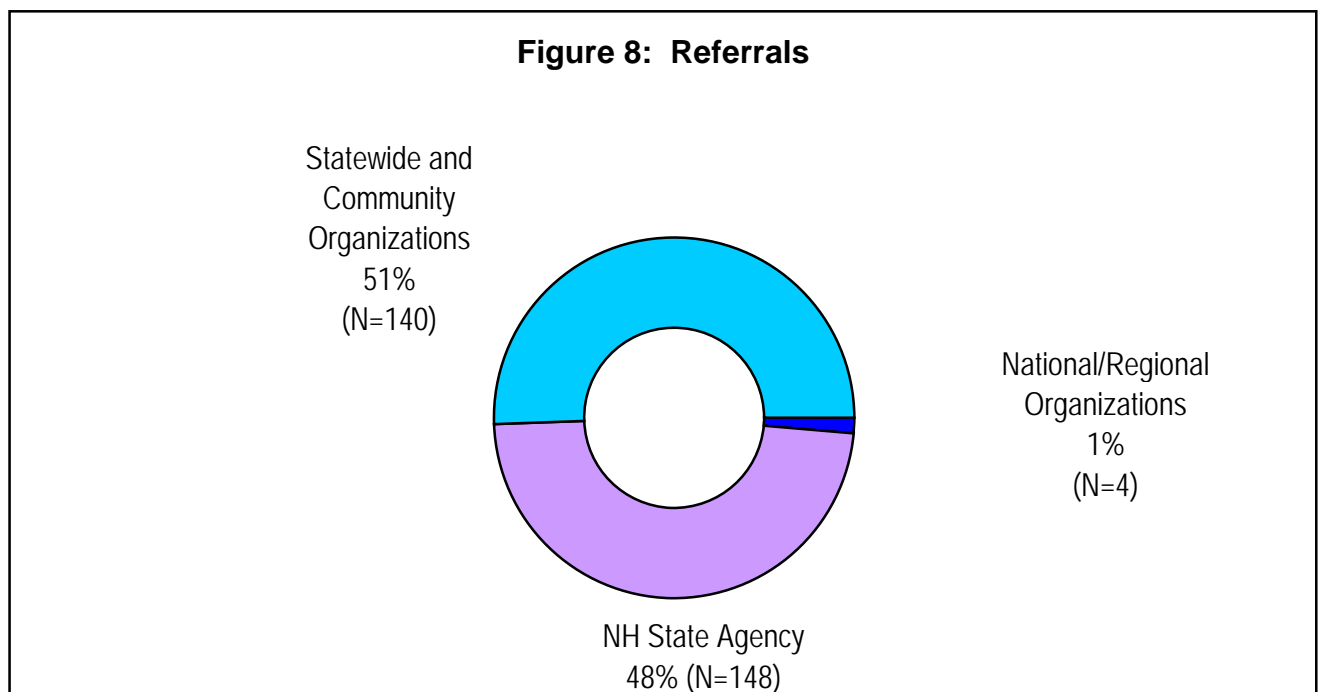


Table 5 Referral Organizations

Level	Agency	Number
National/Regional Organizations	Nation/Region/Listserve	4
NH State Agency	BH/DDS	3
NH State Agency	District Offices	19
NH State Agency	Other State Agency	40
NH State Agency	SMS	78
Statewide and Community Organizations	Area Agency	5
Statewide and Community Organizations	Condition Specific Org	8
Statewide and Community Organizations	Early Intervention	6
Statewide and Community Organizations	Local Health Care	7
Statewide and Community Organizations	Mental Health Ag/Provider	10
Statewide and Community Organizations	NH Family Voices	17
Statewide and Community Organizations	Other	29
Statewide and Community Organizations	Other Disability Orgs	7
Statewide and Community Organizations	Other Parent/Advocacy Groups	5
Statewide and Community Organizations	Parent to Parent	4
Statewide and Community Organizations	Partners in Health	28
Statewide and Community Organizations	Spec Ed/School	3
Statewide and Community Organizations	Specialty provider	12
Statewide and Community Organizations	Town Services	7

Figure 9: Responders to Calls

